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Aboriginal Women's Health Research

Synthesis Project

FINAL REPORT

Prepared for the Centres of Excellence for Women's Health
Research Synthesis Group

by Madeleine Dion Stout,
Gregory D. Kipling
and Roberta Stout

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May, 2001

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CEWH RESEARCH SYNTHESIS GROUP

The Centres of Excellence for Women's Health established the Research Synthesis Group in May 2000. The group's mandate, as approved by the Directors of the Centres of Excellence, is to identify and coordinate reviews and syntheses of research findings across the Centres of Excellence for Women's Health, in selected key areas of work, and to serve as an Advisory Group to the Editor of the CEWH Research Bulletin.

An Aboriginal Women's Health and Research Interest Group Listserv has been set up, sponsored by the Canadian Women's Health Network (CWHN). For more information, please contact the CWHN.

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EXECUTIVE SUMMARY

BACKGROUND

In November 2000, the Centres of Excellence for Women's Health Research Synthesis Group, composed of representatives from each Centre, the Canadian Women's Health Network and Health Canada's Women's Health Bureau, identified Aboriginal women's health research as a priority. Accordingly, the Research Synthesis Group launched an initiative designed to capture the cumulative knowledge and experience generated through Centre activities in the area of Aboriginal women's health, as a basis upon which to establish directions for future work in this area. This paper seeks to contribute to this process in four principal ways:

- By providing an overview of key health and health-related indicators for Aboriginal women in Canada.
- By conducting a critical review and synthesis of research and other initiatives on Aboriginal women's health undertaken or funded by the Centres of Excellence for Women's Health.
- By reporting on the proceedings of the National Workshop on Aboriginal Women's Health Research, held in Ottawa in March 2001.
- By formulating recommendations to serve as the basis for priority-setting in future Aboriginal women's health research activities.

SUMMARY OF KEY FINDINGS

The Aboriginal women's health initiatives undertaken or supported by the Centres of Excellence for Women's Health are characterized by diversity of methodology and approach, as well as being heterogenous in the themes they address and insights they offer. In reviewing the projects, five principal theme areas were identified, encompassing Aboriginal women's health status; violence and sexual abuse; substance abuse and maternal health; health-seeking behaviour; and access to services.

While all of the initiatives undertaken or supported by the Centres probe questions of key concern to Aboriginal women, additional work is needed in a number of areas. In particular, steps must be taken to ensure that research methodologies are clearly articulated and respectful of Aboriginal women's multiple

burdens; that attention be focussed on groups of Aboriginal women whose needs and concerns have been under-represented in previous research; and that research initiatives be reflective of Aboriginal women's linguistic and cultural diversity. Other issues identified in the paper include the lack of sufficient funding to pursue Aboriginal women's health research, and the need to ensure adequate and appropriate follow-up. Also highlighted was the importance of giving Aboriginal women control over research that affects them, along with the need to enhance training and networking opportunities for Aboriginal women researchers, and to foster partnerships and collaboration with both Aboriginal and non-Aboriginal organizations.

SUMMARY OF RECOMMENDATIONS

To promote the indigenization of the research process, it is recommended that the Centres of Excellence for Women's Health:

i) Clearly define options for doing health research on Aboriginal women.

ii) In conjunction with Aboriginal women's health researchers and appropriate Aboriginal organizations, outline a strategy for just, sustainable and inclusive collaborations and partnerships; and educate researchers and research participants about health research and Aboriginal women.

iii) In conjunction with appropriate Aboriginal and non-Aboriginal organizations and Health Canada's Women's Health Bureau, develop a strategy for the incorporation of Aboriginal women's health stories, experiences and knowledge into an analytical framework that can be used as a "lens" when doing research with Aboriginal women.

iv) Work with appropriate Aboriginal and non-Aboriginal organizations to promote a dialogue between academic and community researchers, and address outstanding issues related to health research on Aboriginal women, particularly as these relate to identity, culture and key social categories.

To engage Aboriginal women in the research process, it is recommended that the Centres of Excellence for Women's Health:

i) Recognize Aboriginal women's multiple burdens, including poor health status, poverty, violence, substance abuse, child care and over-surveillance.

ii) Encourage Aboriginal women's health researchers and appropriate Aboriginal and non-Aboriginal organizations to work with Aboriginal women in communities to promote participation in research projects; develop a strategy for re-framing issues in ways that ascribe new meanings and actions to theoretical constructs and intransigent problems; share approaches to mobilize Aboriginal women; and identify mediating structures which would strengthen community-driven research.

iii) In conjunction with the Canadian Women's Health Network, coordinate research and develop policy that would support Aboriginal women's groups; involve researchers deemed to be personally suitable for work with Aboriginal women; protect the rights of both researchers and Aboriginal women; build upon Aboriginal women's strong leadership role in health-related matters at the community level; recognize the evolving capacity of Aboriginal women to conduct research; and show sensitivity to diverse audience groups.

iv) Work with Aboriginal women's health researchers to develop an analytical tool which would assist in establishing research priorities in the area of Aboriginal women's health so as to weigh the consequences of acting or not acting on key health issues; and examine the pain/health/healing paradigm that informs the provision of health care services to Aboriginal women.

v) In conjunction with the Centres of Excellence for Women's Health, Health Canada's Women's Health Bureau and other relevant federal government departments, consider the feasibility of holding an annual meeting on Aboriginal women's health research.

To address gaps and weaknesses in Aboriginal women's health research, it is recommended that the Centres of Excellence for Women's Health:

i) Work with Aboriginal women's health researchers and appropriate Aboriginal and non-Aboriginal organizations to determine when, how and why academic and community methodologies should override, intersect or co-exist with one another; identify and track positive health indicators; facilitate networking by Aboriginal women's health researchers; exploit new information technologies to disseminate and share research findings; undertake analyses which compare and contrast local, regional and international trends, issues and solutions; and articulate both gender- and Aboriginal-based analyses.

ii) Work with Aboriginal women's health researchers to develop culturally-appropriate methodologies; identify model communities such as Alkalai Lake and Hollow Water; develop a knowledge base of key Aboriginal concepts and principles (eg. respect) which may be relevant in the pursuit of health research; situate research in larger social, economic, political, legal and cultural contexts; undertake research which is sensitive to Aboriginal women's diversity; understand the implications of the medicalization of Aboriginal women's health; execute research which supports Aboriginal women's programming needs.

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I. INTRODUCTION

1.1 Background

The Centres of Excellence for Women's Health Program (CEWHP) was announced by the Minister of Health in March 1995 to improve the health status of Canadian women by enhancing the health system's understanding of, and responsiveness to, women's health issues. Funding was subsequently provided for the creation of five Centres of Excellence for Women's Health (CEWHs), selected through a competitive process. In addition, funding was also provided to the Canadian Women's Health Network (CWHN) to undertake national coordination of the networking components of the Program and the building of a national information storage, dissemination and communications function. The Program is managed by Health Canada's Women's Health Bureau.

The five Centres of Excellence, located in Halifax, Montréal, Toronto, Winnipeg and Vancouver, are mandated to improve women's health by generating knowledge, information and policy advice which can be used to make the health system more responsive to women's distinctive health needs. In fulfilling this mandate, the Centres are engaged in a wide range of activities, including health-oriented research, knowledge communication, network building and the provision of advice and information to governments and other stakeholders. In the past three years the Centres have also funded or conducted a number of research projects and other activities addressing the particular health concerns of Aboriginal women across the country.

In November 2000, the CEWHP Research Synthesis Group, composed of representatives from each Centre, the CWHN and the Women's Health Bureau, identified Aboriginal women's health as a priority for synthesis work. In embarking on this initiative, the Research Synthesis Group was seeking to capture the cumulative knowledge and experience generated through Centre activities in the area of Aboriginal women's health, as a basis upon which to establish directions for future work in this area.

1.2 Purpose and objectives

The purpose of this paper is to undertake a critical analysis of CEWH research and other initiatives pertaining to Aboriginal women's health, as a basis upon which to identify key directions for future interventions in this area. Specific objectives may be summarized as follows:

- Provide an overview of key health and health-related indicators for Aboriginal women in Canada.
- Conduct a critical review and synthesis of research and other initiatives on Aboriginal women's health undertaken or funded by the Centres of Excellence for Women's Health.
- Report on the deliberations proceedings of the National Workshop on Aboriginal Women's Health Research (NWAWHR), held at the Odawa Native Friendship Centre in Ottawa on 24-25 March 2001.
- Formulate recommendations to serve as the basis for priority-setting in future Aboriginal women's health research activities.

1.3 Methodology

In preparing this report, a number of information-gathering activities were undertaken. These are summarized below:

- All five Centres of Excellence were canvassed for documentation describing research projects and other initiatives pertaining to Aboriginal women's health.
- Relevant studies and reports were solicited

from key Aboriginal organizations working in the field of Aboriginal women's health.
- A key word search was performed on the Internet, major on-line databases and the library catalogues of universities and relevant government departments in the National Capital Region.
- The deliberations of the NWAWHR, whose purpose was to share knowledge on Aboriginal women's health issues; explore links between research and action to improve Aboriginal women's health; and find ways to strengthen health research by and for Aboriginal women, were documented through detailed note-taking.

It should be noted that Part II encompasses a socio-demographic profile of Aboriginal women, while Part III synthesizes the findings of CEWH-affiliated research, along with stated observations and insights at the NWAWHR workshop. In Part IV means of strengthening Aboriginal women's health research are discussed, and Part V outlines recommendations arising from both the NWAWHR and Centre-affiliated research projects.

II. TOWARDS A PROFILE OF ABORIGINAL WOMEN

2.1 Population overview

In 1996, there were approximately 408,100 Aboriginal women in Canada, out of a total Aboriginal population of 799,000 (Statistics Canada 2000). As Figure 1 shows, roughly 66.3 percent of these women self-identified as North American Indian; 25.2 percent as Métis; 4.9 percent as Inuit; and 3.2 percent as belonging to more than one category.

In absolute terms, Ontario and British Columbia are the provinces with the largest Aboriginal female population, comprising 73,725 and 71,455 individuals respectively. The provinces where Aboriginal women constitute the greatest share of the general female population are Manitoba (11.7%) and Saskatchewan (11.5%). The proportion is even higher in the territories, where Aboriginal women constitute more than 86 percent of Nunavut's total female population, roughly 50 percent in the case of the Northwest Territories and 21.6 percent in the Yukon.

Although many Aboriginal women and men continue to reside on-reserve or in rural areas, there is a growing urban Aboriginal population. In 1996, 171,000 Aboriginal people, comprising approximately 20 percent of the total Aboriginal population, lived in Winnipeg, Edmonton, Vancouver, Regina, Saskatoon, Calgary or Toronto (Statistics Canada 13 Jan. 1998). Many were children under 15 years of age, living with their mothers or other Aboriginal women (Canadian Institute of Child Health 1994).

2.2 Fertility and the life-cycle

National statistics show that Aboriginal women and men[1] are, on average, roughly 10 years younger than their non-Aboriginal counterparts (Statistics

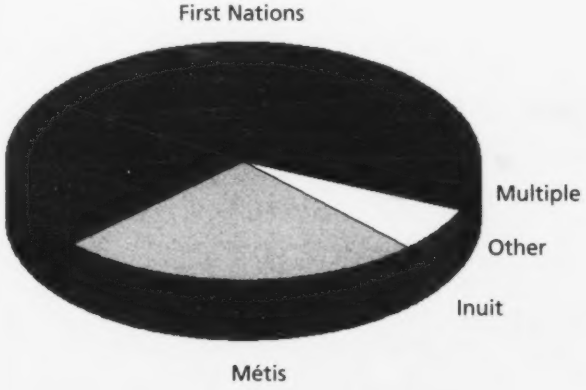


Figure 1 – Female Aboriginal population by ethnicity, 1996 (Statistics Canada 2000)

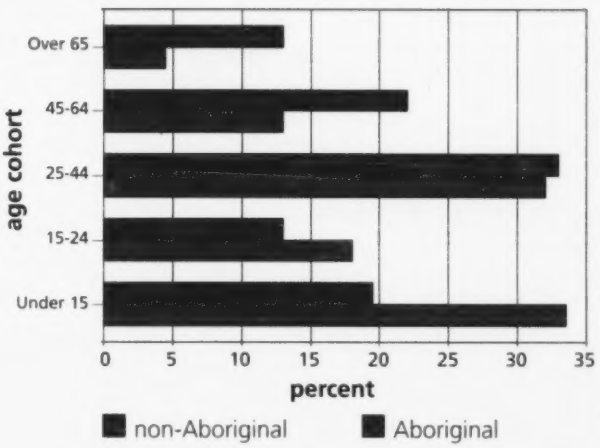


Figure 2 – Aboriginal and non-Aboriginal women by age, 1996 (Statistics Canada 2000)

Canada 13 Jan. 1998). As is made clear in Figure 2, this difference is particularly marked in the under 15 age cohort: 33.6 percent of the Aboriginal female population falls into this category, as compared to just 19.4 percent among the non-Aboriginal female population.

To a significant degree, variability in the age distribution of Aboriginal and non-Aboriginal peoples can be explained with reference to differences in reproductive patterns. For example, 55 percent of Aboriginal mothers are under 25 years of age, and 9 percent are under 18 years of age (Health Canada 2000). Among non-Aboriginal mothers, roughly 28 percent are less than 25 years old, and only 1 percent are under than 18 years of age (Health Canada 2000). Given the relative youthfulness of Aboriginal mothers, it is not surprising that they also tend to have larger families than other Canadian women. Whereas non-Aboriginal women are characterized by a fertility rate of 1.61, the rate for Inuit and Registered Indian women is significantly higher, at 3.4 and 2.5 respectively (Indian and Northern Affairs Canada 1996).

Needless to say, figures such as those cited above hold important implications for policy development in sexual and reproductive health, as they do in matters related to the health of Aboriginal children and adolescents. For instance, scholars have argued that the high rate of adolescent pregnancy in many Aboriginal communities may be one factor helping to explain elevated levels of Aboriginal infant mortality (MacMillan *et al.* Dec. 1996). While the mortality rate for First Nation infants has fallen sharply in recent decades, it remains approximately 1.7 times higher than that of the general population (10.9 per 1,000 live births in the case of the former, as compared to 6.0 in the case of the latter) (PAHO 1999).

Even as the relative youthfulness of Aboriginal women is highlighted, this should not be taken to mean that the issues and challenges experienced by older Aboriginal women can be ignored. As the Native Women's Association of Canada notes, the

> *number of Aboriginal people over the age of 65 is increasing. In 1951 they accounted for 2.2% of the total Aboriginal population compared to 4.8% in 1991 ... This segment of the Aboriginal population is growing three times faster than other age groups and it is estimated that the number of status Indians over 65 will grow by 1.4% between 1991-2001* (1997, p. 19).

[1] The authors have attempted to locate and present national data which highlights the unique characteristics of First Nations, Inuit and Métis women. However, in many cases data obsolescence or non-availability has prevented us from meeting this objective. For this reason, much of the discussion that follows pertains to Aboriginal women in general, or to populations for which national data are readily available (e.g. Registered Indian women).

2.3 Health and well-being

Despite public recognition of past injustices committed against Aboriginal peoples in this country, marginalization and prejudice remain very much present in the daily lives of many community members. While the effects of this marginalization make themselves manifest in any number of ways, few are more telling than statistics that place Canada's Aboriginal population far below their non-Aboriginal counterparts in the United Nations Human Development Index (Toronto Star 12 June 1997). That is to say, even as Canada is praised for affording its people one of the best qualities of life anywhere in the world, Aboriginal women and men are characterized by a health profile one would normally associate with the developing world.

With regard to life expectancy, Canadian women can now expect to live almost 82 years, while the life expectancy at birth of Inuit and Registered Indian women in 1991 was less than 75 (see Figure 3). Even as one acknowledges that gains continue to be made – by 1995 Registered Indian women's life expectancy had risen to 76.2 (Indian and Northern Affairs Canada Feb. 2000) – the gap remains large. While the reasons for this difference are unquestionably complex, socio-economic marginalization, along with the poor health status of many Aboriginal women, helps to skew the end results.

In this context it is not surprising that the age-standardized mortality rate from all causes among First Nations women is substantially higher than it is among Canadian women in general (MacMillan *et al.* Dec. 1996). To a significant degree, this is due to an elevated level of injury- and violence-related mortality among women from First Nation and other Aboriginal backgrounds. For example, between 1989 and 1992, the death rate for First Nations women due to motor vehicle accidents was 24.7 per 100,000 population, and the death rate due to poisoning was 11.7 (RCAP 1996). In contrast, the mortality rates for non-Aboriginal women were 8.3 and 1.2 respectively.

Aboriginal women also experience a much higher suicide rate than that of their non-Aboriginal counterparts, which in turn helps to

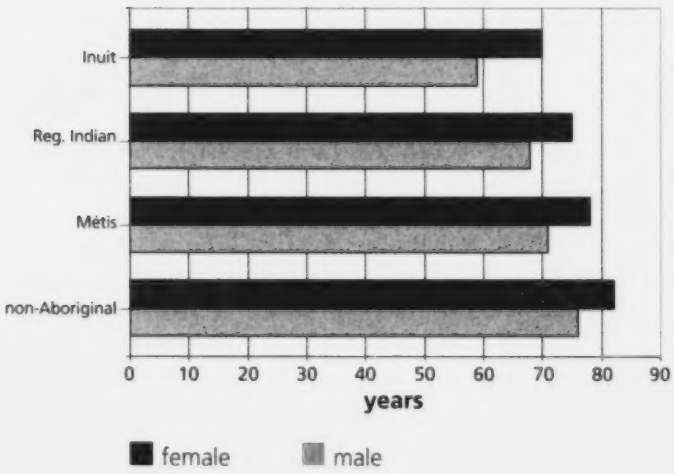


Figure 3 – Life expectancy at birth of Aboriginal and non-Aboriginal people, 1991 (RCAP 1996)

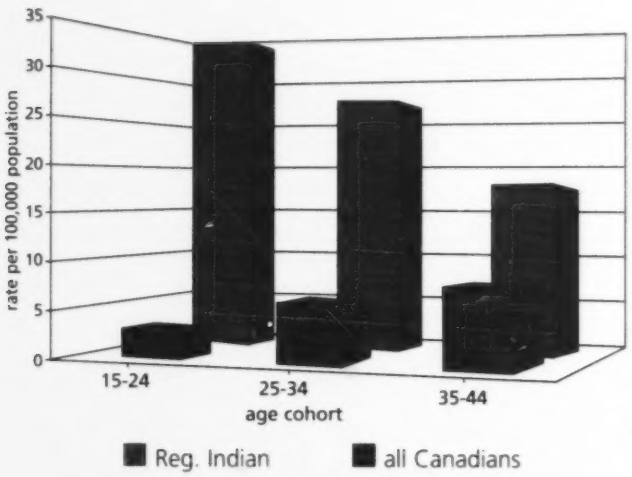


Figure 4 – Suicide rate for Registered Indian and all Canadian women by selected age group, 1989-1993 (Statistics Canada 2000)

explain figures indicating that Aboriginal women are at an elevated risk of death by violence (Health Canada 1999). According to a recent Health Canada report, among Aboriginal women aged 25 to 44, the mortality rate due to violence is five times higher than that among all other Canadian women (ibid. 2000). In this regard, it should also be noted that Aboriginal individuals of either sex are significantly over-represented among Canadian homicide victims, constituting 16.6 percent of the total (Best n.d.).

At the same time, Aboriginal women are also more likely to inhabit a social environment in which substance abuse and spousal violence are widespread (Pauktuutit Mar. 2000; RCAP 1996). Situations like this are highlighted by the fact that alcohol-related hospital admissions are three times higher among Aboriginal women than is the case among the general population (RCAP 1996). Recent studies undertaken in First Nations communities indicate that:

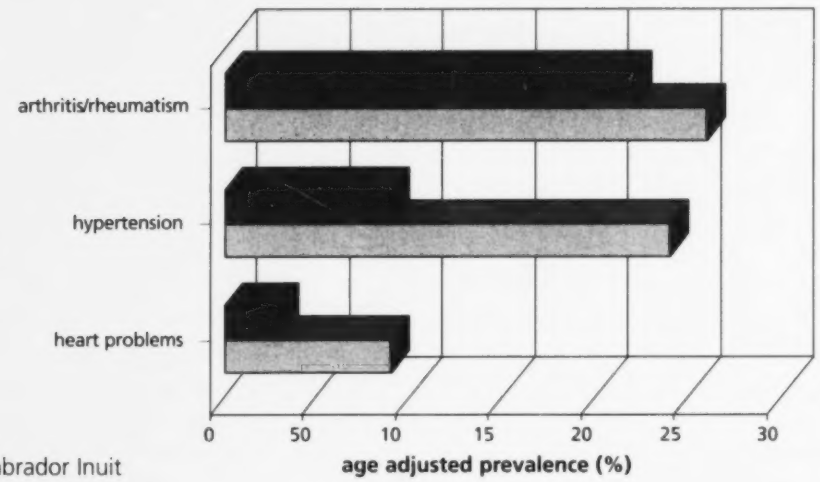
> *At least three-quarters of Aboriginal women have been the victims of family violence, up to 40% of children in some northern Native communities had been physically abused by a family member and the abuse of older adults has been identified as a serious problem in some First Nations communities* (Health Canada Nov. 1999).

As well, Aboriginal women experience much higher rates of incarceration than their non-Aboriginal counterparts. For example, in 1997 First Nations women represented 19 percent of all federally sentenced women, despite the fact that they made up only 2 percent of the general Canadian population (Canadian Association of Elizabeth Fry Societies 2000). Aboriginal women in general were incarcerated at a rate of 16.3 per 10,000 population as of June 1998 (ibid.).

With regard to Aboriginal women's reproductive and sexual health, research has shown that Métis, Inuit and First Nations women are more likely than their non-Aboriginal counterparts to become infected with a sexually transmitted disease (Aboriginal Nurses Association of Canada 1996). As well, Aboriginal women represent a significantly higher proportion of HIV/AIDS diagnoses than non-Aboriginal women (18% as compared to 6%), with well over half of these cases attributable to injection drug use (Health Canada 2000).

The problems discussed above only add to Aboriginal women's physical health, setting them apart from the country's non-Aboriginal female population. By way of example, a relatively large proportion of the former group report having a long-term disability. While the precise rate varies considerably among the different Aboriginal groups, from a high of 9.8 per cent for off-reserve status Indian women to a low of 8.9

Figure 5 – Age-adjusted prevalence of selected chronic diseases for non-Aboriginal and First Nations and Labrador Inuit women (Health Canada Nov. 1999)



per cent for Inuit women, it is in all instances higher than the rate for the non-Aboriginal female population, which is 7.4 per cent (Indian and Northern Affairs 1996).

Although the prevalence of cardiovascular diseases and other chronic illnesses linked to a sedentary lifestyle and high fat, high sugar diet have traditionally been low among Aboriginal peoples, there is evidence to suggest that this situation may be changing. In the case of diabetes, while the incidence of this disease has remained relatively stable among non-Aboriginal Canadians in recent decades, prevalence rates have increased rapidly within the Aboriginal population, who are now thought to suffer from it at a rate two to three times higher than other Canadians (PAHO 1999; RCAP 1996; Health Canada Nov. 1999; ibid. 1999). Moreover, Aboriginal women are believed to be particularly prone to diabetes, contracting the disease at a rate roughly twice that of Aboriginal men (Health Canada 2000).

Aboriginal women have also been shown to be at elevated risk of obesity. In a recent study undertaken in Northern Ontario, 60 percent of adult First Nations women were deemed to be obese (Health Canada Nov. 1999). Research focussing on adult Cree and Ojibwa Indians living in Northern Canada found a "high proportion of overweight in all age and sex groups, with almost 90% of women between the ages of 45 and 54 having a body mass index (BMI) of at least 26 (Health Canada Nov. 1999). According to Health Canada, those with a BMI between 25 and 27 "may lead to health problems in some people" (ibid. 1988)

As Figure 5 makes clear, First Nations and Labrador Inuit women are also more likely to report chronic diseases such as arthritis, hypertension, and heart problems. First Nations women in particular are characterized by a death rate due to ischemic heart disease and stroke which is significantly higher than that of non-Aboriginal Canadian women (PAHO 1999).

Cancer is another disease whose prevalence appears to be increasing within the ranks of the Aboriginal population (Assembly of First Nations 2001). Among Aboriginal women, the incidence

of cervical cancer is deemed to be especially high (Assembly of First Nations 2001; Health Canada 2000). This is underscored by the results of a study undertaken over a 30-year period in British Columbia, which found that the rate of death from cervical cancer for First Nations women was 33.9 per 100,000 population, as compared to 8.1 among non-Aboriginal women.

2.4 Education, employment and income

It is widely recognized that socio-economic factors play an extremely important role in individuals' health status (Lalonde 1974; Federal, Provincial and Territorial Advisory Committee on Population Health 1996). Canada, despite its strong showing in the United Nations Human Development Index, has rated lower in the area of poverty eradication, placing eighth among industrialized countries when ranked according to the Human Poverty Index (UNDP 1999). Although Aboriginal peoples are not alone in experiencing poverty's destructive effects, they are far more likely to be poor than other Canadians (NAPO 1997).

In the area of formal educational attainment, Aboriginal women, while faring substantially worse than the non-Aboriginal female population, are nonetheless more likely than their male counterparts to possess a university degree, or to have pursued some post-secondary or secondary studies (Statistics Canada 2000). Given this, it is not surprising that Aboriginal women experience lower levels of unemployment than Aboriginal men in all age categories, a finding which stands in marked contrast to unemployment trends within the non-Aboriginal population, where gender-based differences are much smaller (see Figure 6).

In this context it is also important to compare Aboriginal women with their non-Aboriginal counterparts: at the same time that non-Aboriginal women were characterized by an unemployment rate of 9.7 percent, the rate stood

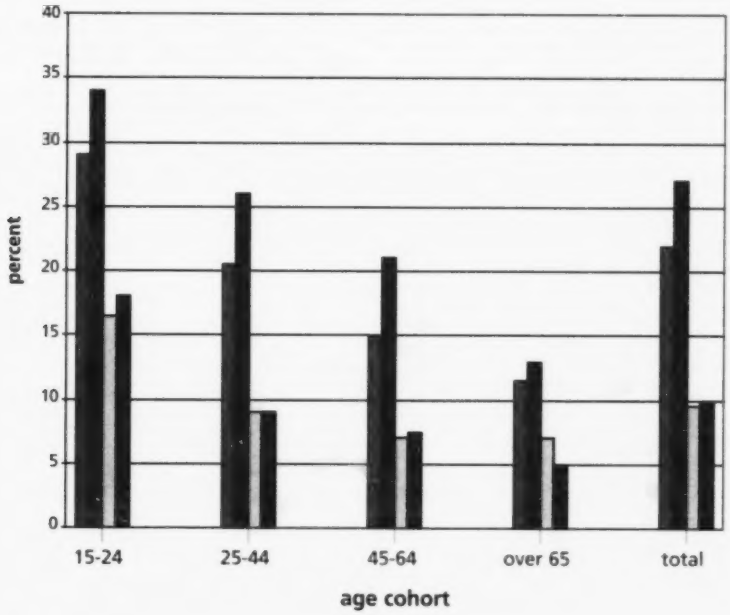
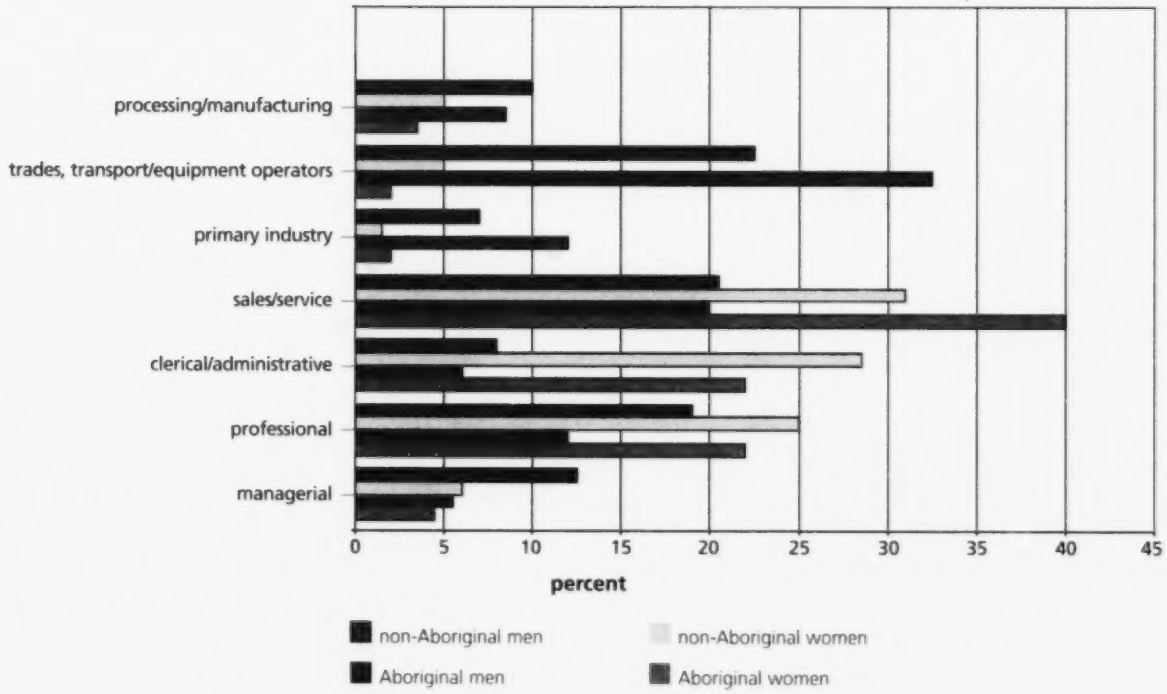


Figure 6 – Unemployment rate of Aboriginal and non-Aboriginal people by age, 1996 (Statistics Canada 2000)

at more than 21 percent among the Aboriginal female population. Such high levels of unemployment are likely to have a direct impact on Aboriginal women's economic status, a view which is confirmed by figures showing an incidence of low income among Aboriginal women which is more than twice that found among the general Canadian female population (42.7% as compared to 20.3%).

Also significant is the fact that, even when Aboriginal women are able to overcome the barriers they face in securing gainful employment, they are nonetheless often relegated to occupations in which part-time hours and low levels of pay are common. As Figure 7 shows, slightly more than 40 percent of Aboriginal women in the Canadian workforce are employed in the sales and service occupational category. Not only does this proportion greatly exceed that characterizing Aboriginal men or non-Aboriginal people of either sex, but it is far above that of the category with the second highest concentration of Aboriginal women, namely clerical and administrative occupations.

Figure 7 – Occupational distribution of Aboriginal and non-Aboriginal people, 1996 (Statistics Canada 2000)



2.5 Conclusion

In the preceding pages, a range of data pertaining to Aboriginal women's health and socio-economic status have been outlined and discussed. Taken as a whole, they serve to underscore the extent to which these women bear the burden of ill-health, premature death and marginalization to a degree unimaginable to much of the country's population. Still, even as the need for action in any number of areas is

acknowledged, recognition must also be given to Aboriginal women's strength and resilience, which has allowed them to move forward and succeed, despite the countervailing forces of racism, prejudice and a colonialist legacy which they are now seeking to reverse.

III. INITIATIVES IN ABORIGINAL WOMEN'S HEALTH: REVIEW OF KEY THEMES AND INSIGHTS

3.1 Aboriginal women's health research in context

Among those with a stake in the issues and challenges facing Aboriginal women in Canada, it has long been argued that this is a population in which policy makers and researchers show little interest. Doubly marginalized as both female and Aboriginal, these women have seldom benefited from sustained research attention that explores, in a substantive fashion, their lives, challenges and strengths.

Admittedly, this situation has improved somewhat over the course of the past 15 years, as Aboriginal women's organizations and their allies have forced decision makers to take notice of the appalling inequities characterizing many Aboriginal women's lives. By the same token much of the work being undertaken remains narrowly focused and is often tangential to the underlying causes of Aboriginal women's marginalization and oppression.

Health-related research is a case in point. Although the Government of Canada has funded research in such areas as childbearing and childbirth as early as the 1950s, much of this work was highly technocratic in nature, and often divorced from broader social and political contexts. More recently, however, the orientation of Aboriginal women's health research has shifted considerably, becoming more critical of existing policies and structures (Pauktuutit Apr. 2001).

At a more general level, research attention has also increasingly focussed on patterns of Aboriginal women and men's usage of the formal health system, with particular emphasis being placed on the nature and scope of access barriers, and the means of overcoming these (SOGC Mar. 2001).

Since the late 1980s, researchers have continued to deal with many of the longstanding issues in Aboriginal women's health, while at the same time addressing a number of emerging concerns, such as HIV/AIDS, diabetes and the implications of Bill C-31. In aAnother notable development is researchers and policy makers' growing interest in health determinants, along with the importance of capitalizing on knowledge already present within Aboriginal communities (Aboriginal Nurses Association of Canada 1993). In the area of HIV/AIDS, researchers are placing greater emphasis on making explicit the links between Aboriginal women's experiences of the disease and the realities of gender-based inequity and socio-economic marginalization (Ship and Norton 2000).

Thus, additional resources need to be channelled into Aboriginal women's health which, relatively speaking, remains under-studied and poorly-understood, despite the innovative, action-oriented research work that has been undertaken in a number of areas. These include projects which explore Aboriginal understanding of health and wellness (Adelson 2000); the high incidence of depression among certain groups of Aboriginal women (Dion Stout 1995), their susceptibility to diabetes and obesity (Martin and Bell 1991; Evers 1991); and finally, their dangerously high rates of smoking and substance abuse (Native Women's Association of Canada 1996).

3.2 Overview of CEWH initiatives on Aboriginal women's health and the NWAWHR workshop

In its final report, the National Forum on Health stated that "women's health involves women's emotional, social, cultural, spiritual and physical well-being, and is determined by the social, political and economic context of women's lives as well as by biology (Health Canada Feb. 1997). To a significant degree, the initiatives undertaken or supported by the Centres of Excellence for Women's Health are reflective both of the Forum's holistic definition of health, and of the increasingly broad range of issues being addressed by researchers and practitioners, many of whom are Aboriginal themselves, in the area of Aboriginal women's health. Additionally, the proceedings of the NWAWHR provide profound insight into participants' concerns and priorities regarding Aboriginal women's health and Aboriginal women's health research. More than 20 First Nations, Métis and Inuit women took part in this meeting, and they came from a wide range of regions, organizations and life experiences. Also present were several non-Aboriginal participants. Workshop participants included representatives of Aboriginal women's and health organizations, researchers, CEWH representatives, and representatives from Health Canada, including the Women's Health Bureau, which provided funding for the event. Discussions at the NWAWHR workshop frequently reflected the questions, concerns and issues arising from the CEWH research initiatives.

Aboriginal women who participated in the NWAWHR workshop made clear that their health is inseparably related to that of their families and communities. In short, the vital role played by Aboriginal women as caregivers, leaders and nurturers could not be emphasized enough.

In preparing this paper, a total of 26 Centre reports were reviewed. As Table 1 makes clear, the bulk of these initiatives were affiliated with the Centre of Excellence for Women's Health –

Centre of Excellence	No. of projects	Percent of total
MCEWH – Halifax	6	23.1%
CESAF – Montréal	9	34.6%
NNEWH – Toronto	1	3.8%
PWHCE – Winnipeg	4	15.4%
BCCEWH – Vancouver	6	23.1%
	26	**100%**

Table 1 – Number of projects affiliated with each Centre

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Consortium Université de Montréal (CESAF), the Maritime Centre of Excellence for Women's Health (MCEWH) and the British Columbia Centre of Excellence for Women's Health (BCCEWH), with a smaller number associated with the Prairie Women's Health Centre of Excellence (PWHCE) and the National Network on Environments and Women's Health (NNEWH).

Based on a review of the CEWH projects, it appears that the majority of the Centres of Excellence provided funding or other forms of support, with responsibility for project development and implementation resting in the hands of proponent organizations and individuals. Even as the Centres' precise roles varied from project to project, networking and developing partnerships between Centre personnel and members of Aboriginal communities and Aboriginal women's organizations were clearly important features of many of the initiatives. This was particularly evident in the case of CESAF, the Quebec Native Women (QNW) and the Aboriginal Women of Montréal (AWM).

Given the range of interests and concerns which underpin the various CEWH projects, it is not surprising that they are highly heterogenous in their objectives, methodologies and outcomes. While more than half of the initiatives may be described as research-oriented, to the degree that they sought to shed light on a particular problem and recommend solutions, the remainder adopted a variety of means of addressing Aboriginal women's health and wellness concerns. In three cases the central aim of the projects was to empower Aboriginal women by holding gatherings where they could learn and share with one another. Other initiatives were focussed on the development of tools which could help these women to access services or make healthy choices in their lives.

As mentioned above, the projects employed a diverse set of methodologies and approaches. In a number of instances, proponents made use of questionnaire surveys and large samples of randomly selected individuals. In other cases, particularly those in which Aboriginal women were the sole focus of research, qualitative methods were generally the preferred strategy, with semi-structured interviews, focus groups and participant observation being among the principal means adopted to elicit the women's knowledge and experiences.

While a range of Aboriginal peoples were considered in the various projects and initiatives, in almost all instances primary attention was focussed on the health-related concerns of First Nations women. Still, Métis and Inuit women were considered in some of the work, and in many cases research was undertaken with groups of Aboriginal women who are traditionally ignored or marginalized. Most notably, these include non-status Indian women, urban Aboriginal women and Aboriginal women in conflict with the law. It should be noted here that the participation and representation of Aboriginal women in research was a recurring theme in the NWAWHR workshop deliberations, and is an issue which will be addressed in detail in a subsequent section of this paper.

Select CEWH initiatives are noteworthy too because of the importance they attach to broad-based results dissemination. In some cases, such as the CESAF-funded diabetes prevention manual, communication proved to be of central concern, since the manual produced had to be accessible in order to be useful to its intended audience. At the same

time, however, many of project proponents committed themselves to multiple forms of dissemination, placing particular stress on presenting the findings in appropriate and meaningful ways for Aboriginal women.

In the view of many workshop participants, results dissemination, although a crucial component of the research process, generally receives insufficient attention in the minds of many project proponents. However, given that it is only through the communication of findings that research is likely to result in action, participants called for the allocation of additional resources in this area.

At the same time, the women voiced strong support for the principle of purposive dissemination. For them, individuals involved in Aboriginal women's health research must focus attention on identifying key audiences, like politicians, community leaders and policy makers, and target outputs accordingly. However, this is not to say that workshop participants were not equally concerned with the issue of results communication at the community level. On the one hand, several women underscored the importance of ensuring that findings reports are available in an accessible format, and are translated into the first language of all prospective readers. On the other, the women also discussed means of sharing the results of research in creative and innovative ways, for example through open line radio programs.

3.3 Major themes and insights from CEWH initiatives and the NWAWHR workshop

As stated previously, the Aboriginal women's health initiatives undertaken or supported by the Centres of Excellence are characterized by

	Health Status	Violence and sexual abuse	Substance abuse and maternal health	Health-seeking behaviour	Access to services	Total
MCEWH Halifax	5	0	0	0	1	6
CESAF Montréal	1	2	1	3	2	9
NNEWH Toronto	0	0	0	0	1	1
PWHCE Winnipeg	0	1	1	1	1	4
BCCEWH Vancouver	0	0	1	0	5	6
Total	**6**	**3**	**3**	**4**	**10**	**26**

Table 2 – Project theme areas addressed by each Centre

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Total	**6**	**3**	**3**	**4**	**10**	**26**

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diversity of methodology and approach, they are equally heterogenous in the themes they address and insights they offer. In reviewing the projects, five principal theme areas are identified, encompassing Aboriginal women's health status; violence and sexual abuse; substance abuse and maternal health; health-seeking behaviour; and access to services.

While these themes will provide a framework around which discussions of the various initiatives will be organized, it should be noted that particular projects may address issues spanning more than one category (as in the case of the PWHCE's *Study of the Service Needs of Pregnant Addicted Women in Manitoba*). In instances such as these, categories of best fit were chosen, while at the same time endeavouring to address the projects' findings in their entirety.

3.3.1 Health status

In all, six of the initiatives under consideration assess the general health status of specific Aboriginal peoples, notably the Mi'kmaq of Nova Scotia and the Inuit and Cree of northern Quebec. Although these projects differ significantly as to their current status (some are complete; others remain on-going) and whether or not men are included in their analyses, they all share a holistic definition of health which extends far beyond the prevalence of particular diseases or associated risk factors.

Perhaps the most ambitious of the initiatives was a 1999 study prepared by the Nova Scotia Mi'kmaq Health Research Group. Involving 723 structured interviews in 13 reserve communities across Nova Scotia, the report offers a detailed profile of the health of children, youth and adults of both sexes. As for Aboriginal women's health, while many of the findings are consistent with other research in areas like female obesity, diabetes and smoking during pregnancy, the report makes a number of significant observations. These include results which show that few Mi'kmaq babies suffer from low birth weight, along with the fact that a large proportion (60%) of women believe their experience at a residential school has contributed to health or well-being problems they may be facing.

Also noteworthy are findings which show an incidence of depression, low self-esteem and substance use among female youth that is significantly higher than that of their male counterparts. Indeed, it is precisely in response to the latter results that members of the Nova Scotia Mi'kmaq Health Research Group launched a second project, employing semi-structured interviews and focus group discussion, to shed further light on Mi'kmaq female youths' stress experiences. Meanwhile, Patricia Doyle Bedwell is also examining perceptions of mental health and well-being among off-reserve First Nations women in the Maritimes, with particular attention focussed on these women's experiences with mental health service providers. As work is continuing on both of these projects at the time of writing, no findings reports are available for analysis.

Other projects supported by the MCEWH include two research initiatives exploring Nova Scotian women's health priorities, along with their perceptions of the determinants of health and well-being. From the outset, it should be noted that neither study focussed exclusively on Aboriginal women. Rather, such women were but one of a number of groups under consideration.

Confirming the results of other studies, Barksdale *et al.* found that Aboriginal women's definition

of health tends to be considerably different than that employed by non-Aboriginal women, and is less likely to fit into such discrete categories as " nce of disease," "good health/feeling well" or "being psychologically fit." Significantly, Aboriginal women also emphasized the toxic role played by racism and sexism in undermining their health and well-being, together with the detrimental effects of poverty, unemployment and culturally inappropriate or inaccessible health services.

A somewhat different approach was adopted by the authors of a CESAF-funded analysis of health issues facing Inuit and Cree women living in northern Quebec. Using information derived from Santé Québec health surveys, Lavallée, Bourgault and Petawabano sought to re-interpret the data from a gendered perspective, followed by focus group discussion of the results with front-line workers in Inuit and Cree communities. Their findings highlighted a number of significant differences between the two groups of women: for example, the incidence of regular smoking among Inuit women was more than twice that of the Cree female population, while Inuit women (14.4%) were considerably more likely to have attempted suicide than their Cree counterparts (4.9%).

By the same token, there was marked convergence of opinion in focus groups where Inuit and Cree front-line workers were asked to identify their greatest health information needs. In short, both groups stressed the importance of ready access to material on healthy childhood development, sex education, nutrition and depression. However, Inuit women in particular indicated the need for studies on the prevalence of Fetal Alcohol Syndrome (FAS) in their communities, along with locally-developed education and prevention materials.

Looking at the larger body of literature on Aboriginal women's health, it is clear that the projects discussed above are reflective of a generalized concern among researchers with Aboriginal women's health status. On the one hand, this is seen in the large-scale health surveys undertaken in the past decade which document the sex-specific incidence of certain diseases and associated risk factors within the Aboriginal population (First Nations and Inuit Regional Health Survey National Steering Committee 1999). On the other, numerous studies have been carried out at the community or regional level which examine the impact of such conditions as diabetes, HIV/AIDS, cancer and depression on Aboriginal women (Aboriginal Nurses Association of Canada 1996; Abbey and Hood 1993). While some of this work continues to be highly technocratic in orientation, in many cases researchers have attempted to make explicit the links between Aboriginal women's poor health status and their socio-economic marginalization (McBride and Bobet 1990).

These links also surfaced at the NWAWHR workshop. From the outset, participants highlighted the fact that Aboriginal women's health problems can only be understood with reference to their social, political and economic realities and histories. This is seen in the continued impact of the colonialist legacy, including residential schools and Bill C-31, on Aboriginal women's health status. Fetal Alcohol Syndrome and Fetal Alcohol Effects were described as a present day example of how socio-economic marginalization is adversely affecting Aboriginal peoples' health. In the words of one participant,

> *In talking to pregnant women who have problems with substance misuse, none are trying to harm the babies they're carrying. Rather, it's*

about the problems these women are having with long-term addiction. It's also about all the things going on in these women's lives, first of all poverty, which forced many to turn to alcohol.

3.3.2 Violence and sexual abuse

Although spousal violence and sexual abuse are by no means limited to Aboriginal peoples in Canada, there can be little doubt that the combined effects of colonization, community stress and substance misuse help to create an environment which exacerbates these types of destructive behaviours (LaRocque 1994; Manyfingers 1994). Indeed, given the high incidence of family violence in many Aboriginal communities, it is not surprising that a great deal of attention has focussed on this issue, with work being undertaken at the national, regional and local levels in a number of policy areas, ranging from health and social services to law enforcement and rehabilitation (Frank 1992; Manyfingers 1994; McEvoy and Daniluk 1995; Native Women's Association of Canada 1997).

Participants at the NWAWHR workshop emphasized the degree of correlation between men's behaviour and women's health status. In other words, the everyday experience of unequal power relations and sexual, physical and emotional exploitation contributes to a decrease in the health of Aboriginal women.

Of the three Centre-affiliated initiatives addressing violence-related matters, two might be described as research-focussed, while one is practice-oriented. In the latter instance, the project proponents received funding from CESAF to implement a two-year community-based program to provide holistic education and support to women survivors of violence. Through its emphasis on personal agency and traditional approaches to healing, the initiative was successful in assisting the participants to overcome their experiences of abuse and become active members of their community.

In another CESAF-supported project, members of the *Centre de recherche interdisciplinaire sur la violence familiale et la violence faite aux femmes* undertook a wide-ranging literature review as a basis upon which to conceptualize the links between violence and health in Aboriginal and non-Aboriginal settings. Not only did Jauvin, Clément and Damant find a general lack of research addressing the inter-relationship between violence and health, but they also noted, with regard to Aboriginal women in particular, that most recent work in this area has emphasized the health-related consequences of violence, including mental health problems, substance abuse and suicidal thoughts. For their own part, the authors argue that violence should be seen as an obstacle to good health, interacting with other health determinants in complex and multi-variate ways.

In an initiative funded by the Prairie Women's Health Centre of Excellence, interviews and focus groups were conducted with a group of roughly 50 women in conflict with the law who self-harm, in an effort to better understand their backgrounds, needs and realities. Approximately 65 percent of the participants were First Nations or Métis, while the remainder self-identified as either Caucasian or "Other." While the research confirmed the results of earlier studies showing a close correlation between childhood experiences of abuse and self-harm, the project found an equally strong relationship between adult experiences of violence and abuse and self-harm. Moreover, Fillmore *et al.* also identified some of the principal areas of need for women who engage in self-harming behaviour, including

most notably communication as an avenue to express emotional pain, and the importance of acquiring a sense of control in their lives as a means of overcoming the hurt which lies at the centre of their self-destructive behaviour.

3.3.3 Substance abuse and maternal health

Despite continuing uncertainty as to the precise number of Aboriginal children affected by Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), these are serious health threats in many communities (First Nations Health Secretariat 1997; Pauktuutit 1998). Accordingly, it comes as no surprise that at least two Centre-affiliated projects deal with issues pertaining to substance abuse among pregnant Aboriginal women.

Turning first to a project undertaken in Manitoba with support from the PWHCE, Caroline Tait examined the backgrounds and service needs of a sample of 74 predominantly Aboriginal pregnant women who had problems with substance abuse. Through a series of interviews and focus groups with both the women and front-line workers, Tait found that participants tended to be highly pragmatic when deciding which services to access, which was often misinterpreted as non-compliance or a lack of motivation by service providers. Significantly, a large majority of the women also reported facing at least one barrier in accessing treatment, even though pregnancy was found to be precisely the time when they could be motivated by service providers to seek addiction services.

In the second case, AWM received funding from CESAF to undertake an examination of substance abuse patterns during pregnancy, as a basis upon which to develop more effective prevention and treatment strategies for urban Aboriginal women, their families and communities. In findings consistent with those of the Manitoba study reviewed above, poverty and victimization by one's partner were shown to be closely associated with women's abuse of substances while pregnant. Not only did AWM find that high risk Aboriginal women often fail to see a clear connection between substance use and negative health consequences for the fetus, but they are most likely to derive benefit from support services which focus on their general reproductive health, and not merely on their substance misuse.

To a large extent, the issues raised in the latter two studies reflect a longstanding concern among researchers to document Aboriginal women's substance use patterns, and to assess their service needs. In particular, a great deal of attention has focussed on means of preventing substance misuse by expectant mothers, leading Marion Mussell to emphasize the importance of not making women feel guilty for drinking (Assembly of First Nations 1997). Rather, "prevention must be connected to understanding .. why people drink and the abuses suffered in our communities" (Ibid., p.48). Meanwhile, others have called for the development of innovative treatment options for pregnant Aboriginal women who misuse alcohol or other substances (Namyniuk *et al.* 1997), along with the use of pre-natal nutrition programs as a vehicle for the discussion and promotion of good lifestyle choices (Robinson *et al.* 1985).

3.3.4 Health-seeking behaviour

In the face of a longstanding tendency within the mainstream research and policy communities to portray Aboriginal women as victims and to pathologize their lives (Dion Stout and Kipling Mar. 1998), it is significant that at least four of the initiatives affiliated with the Centres of Excellence for Women's Health are focused on

either documenting or promoting Aboriginal women's health seeking behaviours.

This is an important step since Aboriginal women, including those who participated in the NWAWHR workshop, are calling for re-orientation of research activities so as to focus attention on forward-looking strategies and the many positive developments in Aboriginal women's lives. As one NWAWHR workshop participant stated, "we need to look at birth instead of death, wellness instead of illness, positive behaviours instead of guilt". Similarly, others there argued that sustained work should be undertaken in the area of Aboriginal women's resiliency, along with the "defining moments" when such women make important choices in their lives, for example when they decide to stop smoking or pursue a more healthy lifestyle.

Significantly, positive choices and experiences were the focus of several of the Centres' research studies. In two cases, CESAF provided financial support to bring together Aboriginal women of diverse backgrounds to a wellness conference in January 1998, and to a series of creativity and leadership skills workshops held between June 1998 and March 1999. By placing emphasis on the sharing of stories and experiences and the development of innate skills and strength of spirit, both projects provided participants with an opportunity to empower themselves and to build relationships with other Aboriginal women. Given this space, wellness conference participants identified issues of particular concern. These include spousal violence, the cultural identity of adoptees, and the need to address the specific health and wellness concerns of older and younger Aboriginal women.

In a preceding section of this report, diabetes was identified as a significant health issue within the Aboriginal female population. In light of this, it is not surprising that one of the Centre-affiliated initiatives sought to help Aboriginal women to deal with this disease by preparing a diabetes prevention and education manual with their specific needs and concerns in mind. Arguing that mainstream approaches to diabetes prevention are often inappropriate in Aboriginal settings, Roy and Fecteau sought to develop an alternative framework based on Aboriginal women's own knowledge and expertise. Through a series of 25 interviews and 9 focus groups, the authors were able to identify successful coping strategies used by Aboriginal women, along with the particular challenges they face in managing the disease. These challenges range from insensitive health professionals to pressure from friends and family members.

The documentation of health seeking behaviours was also at the forefront of a large-scale study funded by the PWHCE. Involving almost 1,200 First Nations people living in reserve communities across Manitoba, the aim of the project was to examine key characteristics which distinguish Aboriginal women and men's health behaviours. Despite a high level of socio-economic marginalization, Elias *et al.* found that First Nations people of both sexes have taken positive steps to improve their health, and are determined to lead a balanced lifestyle.

Still, a number of gender-based differences were apparent. Corroborating the results of other studies, the authors found that Manitoba First Nations women tend to be characterized by a higher level of educational attainment than their male counterparts, but are more likely to rely on income assistance and experience economic instability. At the same time, while a larger proportion of such women were found to have stopped smoking or made positive dietary

changes in their lives, men were deemed more likely to be physically active.

Some of the CEWH-affiliated studies focus on the positive choices many Aboriginal women are making for themselves and their families. This was also discussed by the participants at the NWAWHR workshop. There is an emerging body of research that recognizes the centrality of women's agency in addressing Aboriginal peoples' health concerns. While acknowledging that particular writers have long sought to document and explore Aboriginal women's health-seeking behaviours (Billson 1992; Lowell 1995), it is only relatively recently that the latter has become an issue of wide-ranging concern in the research and policy communities.

To quote one workshop participant: "it is easier to organize around good things…One thing we don't talk about enough is the strengths of women. We tend to speak only when we have bad stories to tell, not good stories to tell".

3.3.5 Access to services

Within the Aboriginal health literature, numerous studies have highlighted the difficulties Aboriginal women face in gaining access to the mainstream health and social services system. Moreover, even when they do make use of such services, they must often contend with racism, cultural insensitivity and lack of Aboriginal personnel (Aboriginal Nurses Association of Canada 1996; ibid. 8 Sept. 2000).

Extensive discussion at the NWAWHR workshop was devoted to Aboriginal women's interactions with health and human service professionals. Indeed, despite claims frequently made by the latter that they treat all people equally, there was widespread agreement that Aboriginal women are often subjected to racism, prejudice or insensitivity when attempting to access health services. According to the NWAWHR participants, this leaves women feeling isolated and marginalized, and prompts many to avoid the mainstream health system altogether.

In particular, several woman argued that more must be done to ensure that health professionals interact in a respectful fashion with the members of communities in which they work. As an Inuk participant made clear, "a lot of the nurses who come to the North lack understanding of our history and culture, so we recommend that they have cross-cultural training before working in our communities."

Significantly, a number of studies from the Centres demonstrate the degree to which geography plays a role in the inaccessibility of services for Aboriginal women. This remains a serious problem in many communities, particularly those in the North. (Pauktuutit Apr. 2001). Moreover, the lack of basic and essential community health services, such as cancer screening, forces women to leave their homes for days or even weeks at a time, turning their lives and those of their family-members upside down in the process.

Problems related to the inaccessibility of health services were also highlighted in a recent Pauktuutit report, which states that a large majority of respondents in Kitikmeot, Qikiqtaaluk, Nunavik and Labrador indicated a need for a local birthing centre so as to provide Inuit women with an alternative to flying South to give birth (ibid). The importance of such centres was underscored by the NWAWHR workshop participants, with one woman in particular arguing that relocation to Southern hospitals is detrimental to the health of Inuit women as it removes them from their social

networks and family support systems. Moreover, it should be noted as well that government policy regarding expectant and birthing Inuit mothers has served to invalidate the role of traditional Inuit midwives (Linehan 1992; Lowell 1995).

Exacerbating geographical barriers to health service availability, Aboriginal women who do not speak English or French confront yet another challenge when attempting to make use of such services. In light of this situation, NWAWHR workshop participants stressed the importance of ensuring that health-related materials and services are available in linguistically and culturally appropriate formats.

Issues related to service needs and access were addressed in at least seven CEWH-affiliated reports. In British Columbia, for example, BCCEWH-supported researchers undertook work in a Carrier First Nation reserve community in order to assess the positive and negative dimensions of Aboriginal women's experiences with mainstream health care services. While Browne, Fiske and Thomas found a number of examples of "affirming" encounters in which health professionals were respectful of the participants' cultural heritages, and shared knowledge and power over health care decisions, there were also many instances of "invalidating" encounters. These included instances in which the women's concerns were dismissed or trivialized; they were judged in stereotypical negative ways; or no regard was shown for their personal circumstances. In turn, these findings prompted the researchers to call for the adoption of health policies and practices which integrate the concept of cultural safety and recognize Aboriginal women's central care-giving role.

The BCCEWH also provided funding in support of a study by Nancy Poole and Barbara Isaac exploring barriers and supports encountered by pregnant and/or parenting women entering addictions programs in Vancouver and Prince George. Of the 47 women who agreed to take part in the project, 40 percent were Aboriginal. The participants identified several important barriers in the way of treatment, including shame, fear of losing their children and fear of prejudicial treatment. At the same time, a number of supports were also highlighted, ranging from support provided by professionals to supportive friends and family members. In light of their research subjects' experiences, Poole and Isaac made a series of recommendations, encompassing the need to address the stigma, shame and prejudice experienced by substance-abusing mothers and pregnant women, to the importance of ensuring that comprehensive care is available to women and their families.

NWAWHR workshop participants also argued that Aboriginal women tend to remain invisible to the mainstream health and social services system except at particular moments in their lives, for example during pregnancy, when they are subjected to a high degree of surveillance and coercive practices. This is particularly the case among women who receive social assistance. Not only do they tend to be stigmatized by service providers who see them as non-compliant if they should happen to miss an appointment, but they are monitored by neighbours who are prepared to report them for any perceived transgression.

Meanwhile, the health experiences of Aboriginal women living in a highly marginalized Vancouver neighbourhood were the focus of a NNEWH-affiliated study by Cecilia Benoit and Dena Carroll. Through 25 interviews with service providers and a series of three focus groups with Aboriginal women, the authors

sought to assess the degree to which the latter's service needs were being met by the Vancouver Native Health Society (VNHS), an urban Aboriginal health centre located in the city's Downtown Eastside.

While focus group participants were generally positive in their assessment of some aspects of VNHS programming, such as the non-judgmental and supportive environment which characterizes the Society's Sheway Project for substance-using pregnant women, they also identified a number of significant access barriers. Among those cited was the lack of sufficient security and anonymity when using the VNHS' walk-in clinic, which is frequented mainly by male clients; the dominance of Western approaches to counselling to the exclusion of more traditional forms of healing; and the general lack of female health personnel on staff. Thus, not only do Benoit and Carroll call for the implementation of measures to enhance both the quantity and appropriateness of health and social services available to Aboriginal women in the Downtown Eastside, but they also emphasize the importance of asking Aboriginal women themselves about their needs and priorities.

In an extensive evaluation of the first five years of the Sheway Project conducted by Nancy Poole from the BCCEWH, the perspectives of the women who had used Sheway's program were key to the process. Art expression and focus group discussions facilitated the program users in defining how Sheway had helped them. In addition, birth and health outcomes of women and their children were gathered through a file review and key informant interviews. Many of the women using Sheway are Aboriginal and experience poverty, hunger, little social support and difficulties surrounding apprehension and custody of their children. The results showed that Sheway had improved the birthweights of babies and the nutritional status of mothers considerably over the years, but still needs to develop a more proactive drug and alcohol program and a better system for assessing developmental delays of infants and toddlers.

Among NWAWHR workshop participants, considerable emphasis was placed on the need to provide support in tandem with services. Lack of support has proven devastating to the social fabric of many Aboriginal communities and families, with one participant criticizing the non-supportive stance adopted by child welfare agencies when removing an Aboriginal woman's baby on account of substance misuse:

> *One thing I've seen is that agencies will tell women to do A, B and C to get her baby back. However, they don't help the woman do those things, and then when she does all those things, she gets the child back, but has no support, and then falls back on the same problems, and then the baby gets taken away again.*

In a similar vein, NWAWHR workshop participants noted that even when services are readily available, they may be culturally inappropriate in design or the manner in which they are delivered, rendering them inaccessible. Accordingly, Aboriginal women may not make use of such services, again resulting in a decrease in their overall health. This point was emphasized by one of the women present at the workshop, who indicated that HIV-positive Inuit women living in Montreal tend to die very quickly, simply because there is a lack of health and social services appropriate to their needs and realities.

Urban Aboriginal women's wellness needs and access to services were also addressed in two

CESAF-funded reports. In the first case, the author, Caroline Tait, made use of a range of methods, including interviews, participant observation and focus group discussion, in order to gauge the extent to which Aboriginal women living in Montréal are well-served by available health and social services. Not surprisingly, in many cases participants had experienced problems with non-Aboriginal social workers, were stigmatized when they attempted to use their status cards in order to obtain health care, or were unable to access needed services (e.g. in the area of HIV/AIDS) because organizations were under-resourced or had a policy of zero tolerance of alcohol and drug consumption. Also significant are Tait's findings in the area of abortion availability. While she found a significant demand for such services among Aboriginal women in Montréal, the fact that many community members are strongly opposed to it prevented such women from seeking support or counselling from Aboriginal organizations.

As part of the same project described above, the AWM, responding to difficulties Aboriginal women often experience in accessing or finding out about needed services, was in the process of developing an Urban Aboriginal Women's Wellness Resource Centre, where individuals would have been able to go in order to obtain information on culturally sensitive programming in areas touching upon health and wellness. Unfortunately, the AWM no longer exists due to lack of funding.

Along somewhat different lines, the MCEWH provided support to a graduate student at Dalhousie University who was undertaking research on access to traditional medicine among Mi'kmaq women and men. Focussing her attention on the community of Indian Brook, Pereira found that while such medicine remains generally accessible, barriers have emerged in a number of areas. By way of example, she cites the impact of pollution, economic development and private property ownership on areas where traditional medicines are harvested.

Meanwhile, the Prairie Women's Health Centre of Excellence issued a developmental grant in support of a project examining the education needs of Aboriginal women with disabilities living in Manitoba. A focus group was held in July 2000, with participants highlighting the barriers and challenges they have experienced in attempting to pursue their studies. Issues cited by participants include discrimination and prejudice, conflicting childcare responsibilities, lack of sufficient funding, and the non-availability of culturally appropriate services off-reserve.

In sum, a series of issues have been identified which must be addressed if Aboriginal women are to enjoy better health throughout their lives. NWAWHR workshop participants' vision of the future entails a re-orientation of existing models, approaches and practices, along with measures designed to make the health system more accessible and supportive of Aboriginal women and their families (see Appendix III:Visioning Aboriginal women's health research).

Services must respect, be sensitive to and reflect the rich traditional, cultural, geographical and linguistic diversity of Aboriginal peoples in Canada. Participants at the NWAWHR workshop emphasized repeatedly the impact of cultural and linguistic barriers, arguing that health-related materials and services are generally available only in English or French, rather than an Aboriginal language.

At the NWAWHR workshop, cross-cultural training of non-Aboriginal health professionals

working in Aboriginal communities was proposed so as to increase their appreciation and awareness of Aboriginal peoples' realities. Alternatively, increased involvement of Aboriginal peoples in the development and delivery of community health programming was seen as a way of promoting respectful, high quality care for Aboriginal women. As one woman from the NWAWHR workshop argued, political leaders must lend their support by providing assistance to Aboriginal students wishing to go to medical school, and by making sure that Aboriginal communities' schools have sufficient resources and facilities to deliver high quality education.

Significantly, a number of workshop participants also highlighted the need to provide adequate support to Aboriginal women employed as health professionals. Not only are they likely to have experienced barriers within the educational system and in obtaining employment, but they are also frequently faced with mistrust on the part of Aboriginal clients. As one participant remarked, "we have to show our people by working twice as hard that we know what we're talking about."

Moreover, the NWAWHR workshop participants argued that cultural reclamation is also vital if Aboriginal peoples are to enjoy improved health, for example by providing them with an opportunity to learn about their history and traditional ways of well-being. This is in keeping with a large body of literature showing that Aboriginal women derive the greatest benefit from services and resources that are relevant to their cultural contexts and integrate traditional approaches to health and healing. This finding is also reflected in many of the initiatives affiliated with the Centres of Excellence for Women's Health. For instance, they show Inuit women of Northern Quebec voicing a strong desire for locally-developed FAS/FAE prevention and education tools, and First Nations women across the country emphasizing the importance of using traditional knowledge to foster community health and wellness.

Finally, NWAWHR workshop participants insisted that funding must be provided to ensure the availability of required health services to Aboriginal women in the communities in which they live. Furthermore, a number of participants also noted the difficulty which Aboriginal women's organizations often experience in connecting with agencies that can assist with funding arrangements.

IV. SINGLING OUT THE RESEARCH PROCESS

While all of the initiatives undertaken or supported by the Centres of Excellence for Women's Health show a strong commitment to the pursuit of research which probes questions of concern to Aboriginal women, there are a number of areas that could benefit from additional attention. In order to address these concerns, workshop participants indicated a pressing need for new models and approaches in Aboriginal women's health research. At the most fundamental level, this would involve concrete action designed to "indigenize" the research process, both to make it more reflective of Aboriginal women's own life experiences, as well as more grounded in traditional or grass-roots approaches to knowledge and learning.

While recognizing that Aboriginal women's health research has benefited from the attention of highly qualified and committed individuals and organizations, NWAWHR workshop participants were nonetheless unanimous in

arguing that much more could be done to strengthen these activities in the future. They concede that in all too many cases, research has been poorly conceived or failed to address key concerns of community members.

As participants made clear, these weaknesses have resulted in a variety of problems, which must be addressed if indigenization of the research process is to occur. In particular, steps must be taken to ensure that research methodologies are clearly articulated and respectful of Aboriginal women's multiple burdens; that attention be focussed on groups of Aboriginal women whose needs and concerns have been under-represented in previous research; and that research initiatives be reflective of Aboriginal women's linguistic and cultural diversity. Other issues identified include the lack of sufficient funding to pursue Aboriginal women's health research, and the need to ensure adequate and appropriate follow-up. Also highlighted is the importance of giving Aboriginal women control over research that affects them, along with the need to enhance training and networking opportunities for Aboriginal women researchers, and to foster partnerships and collaboration with both Aboriginal and non-Aboriginal organizations.

4.1 Research methodologies

In reviewing the reports prepared by CEWH-affiliated researchers, a notable area of concern was the impact of conflicting responsibilities on prospective research participants. In a number of cases, interviews had to be cancelled because of women's time constraints, resulting in the loss of these individuals' knowledge and insight. In other instances, authors noted difficulties in developing and maintaining fruitful relationships with partner organizations, including Centres of Excellence themselves. This show s that initiatives could benefit from a more transparent articulation of the methodology and criteria for analysis. On the one hand, this is seen in cases where the authors failed to make clear their sample size, research methods and procedures for choosing study participants. On the other, projects involving both Aboriginal and non-Aboriginal women sometimes lacked a sufficiently clear breakdown of their findings by Aboriginal status.

4.2 Funding

Proponents of studies undertaken through the Centres cited the lack of sufficient financial support or overly restrictive funding guidelines as barriers in implementing their research or project objectives. Among those taking part in the NWAWHR workshop, several women shared stories of how funding limitations had affected their research activities. In the words of one participant, "research takes time, and there's often a lack of money to carry projects through." In light of these experiences, not only did the women call for Aboriginal women's research be made a funding priority at all government levels, but they devoted particular attention to the cost of executing projects in northern or remote communities. Accordingly, they argued that in these cases funding bodies should ensure that additional resources are available for travel, accommodation and language interpretation.

4.3 Recognition of diversity

Although Centre-affiliated studies have generally confirmed the view that Aboriginal women's health is worse than that of other Canadian women, they have also highlighted a number of important differences within the Aboriginal female population. For example, James Bay Cree and Inuit women from the Nunavik region, despite living in relatively close proximity to one another, differ significantly in terms of their smoking patterns, risk of high blood pressure and

propensity to have had suicidal thoughts. Similarly, among Mi'kmaq women, the proportion having low birth weight babies was found to be considerably lower than either other Aboriginal women, or the Canadian female population in general. Taken together, these findings show that one must be cautious in making generalizations about Aboriginal women's health. As well, regional and community-based studies are crucial if one is to develop a nuanced understanding of the health-related challenges facing Aboriginal women across Canada.

Even as NWAWHR workshop participants acknowledged the contributions of the Centres of Excellence to Aboriginal women's health research, they signalled the under-represen-tation of Inuit, Métis, Two-Spirited Aboriginal women, Aboriginal women living in communities north of 60, as well as older Aboriginal women. This oversight is reflective of a broader tendency among researchers and policy makers to subsume the diversity of Aboriginal women's issues under those of the general Aboriginal population. Research needs to be undertaken which addresses the lack of baseline health data of these under-represented groups recognizing the uniqueness and diversity of Aboriginal women's needs and concerns.

Furthermore, emphasis was also placed on the importance of unc rtaking local and regional studies, while at the same time investing in national-level research. Data quality was another issue touched upon by workshop participants, with a number of women arguing that categories used in data collection are sometimes poorly conceived, and disaggregated data are often not available. In the view of participants, neither geography, location, nor financial issues should constrain the pursuit of representative research on Aboriginal women's health.

4.4 Respect for Aboriginal control and consent in health research

Among NWAWHR workshop participants, there was general agreement that Aboriginal people should be in full control of the research process, from the planning stages to final report writing and dissemination. Moreover, the women cited a number of reasons why this should be the case. For example, many felt that Aboriginal women and men have a distinct "lens" which allows them to examine community concerns in unique and insightful ways. At the same time, participants also highlighted Aboriginal peoples' reservations about giving free rein to outside researchers who are not familiar with local values and traditions, and have no long-term interest in the communities in which they are working. As one woman put it,

> *I've been around long enough, and one of the things I know is that Aboriginal people work with Aboriginal people, and while I don't want to say that we don't want to work with others, Aboriginal people have a lot of fears ... Although it's true we'd like support from very experienced researchers, the research belongs to us. Because you have to remember is that Aboriginal women often have a different perspective from other women.*

Voices were also raised at the Workshop in favour of the twin principles of community consent and community approval when undertaking research. While some stressed the importance of adequately explaining the research goals and methodology to participants, other cited the Assembly of First Nations' commitment to ownership, control, access and permission (OCAP) as a template that could be applied in many areas of Aboriginal women's health research.

4.5 Setting priorities in Aboriginal women's health research

During the course of their deliberations, the women attending the NWAWHR workshop argued that there is a pressing need to prioritize Aboriginal women's health research needs. Issues raised by participants as requiring urgent attention include the health implications of Aboriginal women's relocation to urban areas; homicide-related mortality rates and associated risk factors; issues related to AIDS and HIV infection among urban Inuit women, particularly in Montreal; and the inter-relationship between poverty, education and health.

4.6 Capacity and human resources development

On several occasions during the course of the NWAWHR workshop, participants noted that Aboriginal women's organizations like the Native Women's Association of Canada, Aboriginal Nurses Association of Canada and Pauktuutit Inuit Women's Association have many years of experience in pursuing health research. As one woman put it, "it is very important to recognize the resident expertise within the Aboriginal communities and the political leadership that exists within our organizations." Thus, for many participants, it is vital that existing knowledge and resources in the area of Aboriginal women's health be fully exploited before investing in new projects that may simply be restating what is already known.

NWAWHR workshop participants also discussed the issue of research standards, arguing that rigorous methods and high quality data are essential if decision makers are to be convinced of the need for action on Aboriginal women's health issues. At the same time, standards are also important to assess researchers' skills and ensure their personal suitability for work in Aboriginal communities. Moreover, equally important for many of the women present at the workshop is the need to invest in Aboriginal women's capacity to undertake their own research. Specifically, several participants suggested that training workshops and other activities be developed which provides Aboriginal researchers with an opportunity to develop their skills and knowledge base.

4.7 Partnership and collaboration

In the view of many NWAWHR participants, there is considerable scope for collaboration and partnership-building between organizations involved in Aboriginal women's health research and non-Aboriginal organizations. That is to say, because issues like FAS and FAE affect a wide range of peoples and communities, both Aboriginal organizations and their non-Aboriginal counterparts could benefit from information sharing and other forms of joint action.

At a more general level, NWAWHR workshop participants identified a number of groups and organizations which Aboriginal women's health researchers may wish to collaborate more closely with or approach for funding. These include universities, trade unions and community leaders. While one woman in particular stressed the usefulness of a strong mediator between communities and institutional resources when undertaking grass-roots or community-based research, others highlighted the difficulties in establishing links with non-Aboriginal organizations. As one woman stated,

> *I think there's a number of organizations out there doing interesting work that could get linked up with Aboriginal communities. However, the problem is often we don't know*

who to connect with to make things happens, and the higher echelons of Health Canada don't seem interested in pursuing this.

4.8 CEWH involvement in Aboriginal women's health research

In addition to inter-organizational collaboration, individuals attending the workshop argued that Aboriginal women's health researchers must be provided with more networking opportunities and means of obtaining peer support. In particular, there was general agreement that the CEWHP could play a constructive role in facilitating the development of a national researchers' database, as well as a network that would communicate by means of electronic mail or other forms of Internet-based communication. Moreover, the women were especially adamant that the enthusiasm generated at the NWAWHR workshop not be wasted, and that a follow-up meeting be held to discuss progress in addressing Aboriginal women's health research needs.

During the course of their deliberations, NWAWHR workshop participants also considered how best the CEWHP might support Aboriginal women's health research in the future. In framing their discussion, the women noted that the Centres have not always done enough to raise awareness among Aboriginal women of their existence and mandate, nor have they focussed sufficient attention on the health-related concerns of Inuit women and Aboriginal women living in the North. While no clear consensus emerged as to whether or not an exclusively Aboriginal Centre of Excellence for Women's Health should be established, a number of participants indicated that, at a minimum, a national advisory committee should be struck in order to provide guidance to the Centres when dealing with issues that touch upon Aboriginal women's health.

4.9 Action and follow-up

For many NWAWHR workshop participants, Aboriginal women's health research has often been characterized by insufficient follow-up on issues raised during the course of the research process. In the words of one woman,

There is a message that the research has not been as appropriate as it could have been. But once the research has done, we have to do whatever it takes to act on this research. We owe this to the people who participated ... As it stands, people participate, and then they wait, they wait, they wait, and nothing changes. I think this is why people are leery of participating in yet another project that might be even more invasive.

The participants made a number of recommendations as to how this problem might be addressed. In the first instance, it was widely agreed that individuals asked to take part in a study should be provided with adequate support to deal with the potentially traumatic memories re-awakened by the researcher's questions. As well, there was a strong consensus among those present at the workshop that research must be both action-oriented and acted upon. In other words, not only must proponents seek to prioritize those projects which are most likely to address Aboriginal women's health concerns and improve their quality of life, but they must also seek ways of promoting change based on the research findings.

V. RECOMMENDATIONS

Having addressed key issues and concerns arising from both CEWH-affiliated research and workshop participants' deliberations, attention will now be turned to the task of identifying actions needed to improve Aboriginal women's

health and Aboriginal women's health research in the future. Recommendations are grouped under three principal headings.

5.1 To promote the indigenization of the research process, it is recommended that the Centres of Excellence for Women's Health:

i) Clearly define options for doing health research on Aboriginal women.

ii) In conjunction with Aboriginal women's health researchers and appropriate Aboriginal organizations,
   a) outline a strategy for just, sustainable and inclusive collaborations and partnerships; and
   b) educate researchers and research participants about health research and Aboriginal women.

iii) In conjunction with appropriate Aboriginal and non-Aboriginal organizations and Health Canada's Women's Health Bureau, develop a strategy for the incorporation of Aboriginal women's health stories, experiences and knowledge into an analytical framework that can be used as a "lens" when doing research with Aboriginal women.

iv) Work with appropriate Aboriginal and non-Aboriginal organizations to:
   a) promote a dialogue between academic and community researchers, so as to encourage a greater understanding and acceptance of community perspectives, realities and definitions about life and health; and
   b) address outstanding issues related to health research on Aboriginal women, particularly as these relate to identity, culture and social categories like sexual orientation, geographical location, race, age, class and disability.

5.2 To engage Aboriginal women in the research process, it is recommended that the Centres of Excellence for Women's Health:

i) Recognize Aboriginal women's multiple burdens, including poverty, violence, substance abuse, child care and over-surveillance.

ii) Encourage Aboriginal women's health researchers and appropriate Aboriginal and non-Aboriginal organizations to work with Aboriginal women in communities to:
   a) promote participation in research projects as a means of improving women's lives and health;
   b) develop a strategy for re-framing issues in ways that ascribe new meanings and actions to theoretical constructs like colonization and intransigent problems like family violence;
   c) share approaches which serve to mobilize Aboriginal women to create, develop, conduct and evaluate research projects; and
   d) identify mediating structures which would strengthen community-driven research.

iii) In conjunction with the Canadian Women's Health Network, coordinate research and develop policy that would:
   a) support Aboriginal women's groups which are struggling to keep up interest, energy and resource levels;
   b) involve researchers who are deemed to be personally suitable for work with Aboriginal women;
   c) protect the rights of both researchers and Aboriginal women, while enhancing their respective roles and responsibilities;
   d) build upon Aboriginal women's strong leadership role in health-related matters at the community level;
   e) recognize the evolving capacity of Aboriginal women to conduct research; and

f) show sensitivity to diverse audience groups by producing multilingual reports in both academic and community-oriented formats.

iv) Work with Aboriginal women's health researchers to:
   a) develop an analytical tool which would assist in establishing research priorities in the area of Aboriginal women's health so as to weigh the consequences of acting or not acting on key health issues; and
   b) examine the pain/health/healing paradigm that informs the provision of health care services to Aboriginal women.

v) In conjunction with the Centres of Excellence for Women's Health Program, Health Canada's Women's Health Bureau and other relevant federal government departments, consider the feasibility of holding an annual meeting on Aboriginal women's health research.

5.3 To address gaps and weaknesses in Aboriginal women's health research, it is recommended that the Centres of Excellence for Women's Health:

i) Work with Aboriginal women's health researchers and appropriate Aboriginal and non-Aboriginal organizations to:
   a) determine when, how and why academic and community methodologies should override, intersect or co-exist with one another;
   b) identify and track positive health indicators, including resiliency, spirituality, everyday health strategies and "defining moments" in Aboriginal women's lives;
   c) facilitate networking by Aboriginal women's health researchers;
   d) exploit new information technologies, including the Internet and electronic mail, to disseminate and share research findings;
   e) undertake analyses which compare and contrast local, regional and international trends, issues and solutions; and
   f) articulate both gender- and Aboriginal-based analyses.

ii) Work with Aboriginal women's health researchers to:
   a) develop culturally-appropriate methodologies;
   b) identify model communities such as Alkalai Lake and Hollow Water;
   c) develop a knowledge base of key Aboriginal concepts and principles (eg. respect) which may be relevant in the pursuit of health research;
   d) situate research in larger social, economic, political, legal and cultural contexts;
   e) undertake research which is sensitive to Aboriginal women's diversity;
   f) understand the implications of the medicalization of Aboriginal women's health;
   g) execute research which supports Aboriginal women's programming needs.

REFERENCES

Abbey, S. and Hood, E. 1993. "Psychiatric consultation in the Eastern Canadian Arctic: mental health issues in Inuit women in the Eastern Arctic." *Canadian Journal of Psychiatry*. Vol. 38. No. 1, pp. 32-35.

Aboriginal Nurses Association of Canada. 8 September 2000. *Survey of Nurses in Isolated First Nations Communities: Recruitment and Retention Issues*. Ottawa: The Association.

_____. 1996. *HIV/AIDS and its Impact on Aboriginal Women in Canada*. Ottawa: Health Canada.

_____. 1993. *Traditional Medicine and Primary Health Care Among Canadian Aboriginal People: A Discussion Paper with Annotated Bibliography*. Ottawa: The Association.

Adelson, N. 2000. *'Being Alive Well': Health and the Politics of Cree Well-Being*. Toronto: University of Toronto Press.

Assembly of First Nations. 2001. "Chronic conditions." http://www.afn.ca/ [Accessed 19 Feb. 2000].

_____. 1997. *Sharing our Healing: National Health Conference, Beaupré, Quebec, June 25-27, 1997*. Ottawa: The Assembly.

Best, B. n.d. "Death by murder." http://www.benbest.com/lifeext/murder.html [Accessed 19 Apr. 2001]

Billson, J. 1992. "Standing tradition on its head: role reversal among Blood Indian couples" in D. Miller, C. Beal, J. Dempsey and R. Heber [eds.]. *The First Ones: Readings in Indian/Native Studies*. Craven: Saskatchewan Indian Federated College, pp. 215-225.

Canadian Association of Elizabeth Fry Societies. 2000. "Human and fiscal costs of prison." http://www.elizabethfry.ca/eweek00/factsheet.htm [Accessed 19 Apr. 2001]

Canadian Institute of Child Health. 1994. *The Health of Canada's Children: A CICH Profile*. 2nd edition. Ottawa: the Institute.

Dion Stout, M. and Kipling, G. July 1999. *Aboriginal Peoples and Bill C-31: Position Paper*. Ottawa: National Association of Native Friendship Centres.

_____. 1999. *Report of the Aboriginal Roundtable on Sexual and Reproductive Health in Preparation for the Five Year Review of the International Conference on Population and Development, February 21-22, 1999, Ottawa*. Ottawa: Government of Canada.

_____. March 1998. *Aboriginal Women in Canada: Strategic Research Directions for Policy Development*. Ottawa: Status of Women Canada.

Dion Stout, M. 1995. *Social and Economic Factors Affecting Aboriginal Women's Mental Health: A Theoretical Perspective*. Ottawa: Native Physicians of Canada.

Evers, S. 1991. "Dietary intake and nutritional status of Canadian Indians: a review" in Postl, B., Gilbert, P., Goodwill, J., Moffatt, M., O'Neil, J., Sarsfield, P., Young, T. [eds.] *Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health*. Winnipeg: University of Manitoba Press, pp. 731-734.

Federal, Provincial and Territorial Advisory Committee on Population Health. 1996. *Report on the Health of Canadians*. Ottawa: The Committee.

First Nations and Inuit Regional Health Survey National Steering Committee. 1999. *First Nations and Inuit Regional Health Survey: National Report 1999*. Ottawa: The Committee.

First Nations Health Secretariat. 1997. "At a glance: facts on FAS/FAE." *First Nations Health Bulletin*. Vol. 7, pp.13.

Frank, S. 1992. *Family Violence in Aboriginal Communities: A First Nations Report*. Victoria: Ministry of Women's Equality.

Health Canada. 2000. "Facts and issues: the health of Aboriginal women." http://www.hc-sc.gc.ca/women/english/facts_aborig.htm [Accessed 16 Feb. 2001].

_____. November 1999. *A Second Diagnostique on the Health of First Nations and Inuit People in Canada*. Ottawa: The Department.

_____. 1999. *Toward a Healthy Future: Second Report on the Health of Canadians*. Ottawa: The Department.

Indian and Northern Affairs Canada. February 2000. *Basic Departmental Data*. Ottawa: The Department.

_____. 1996. *Aboriginal Women: A Demographic, Social and Economic Profile*. Ottawa: The Department.

_____. 1988. "Body Mass Index." http://www.hc-sc.gc.ca/hppb/nutrition/bmicalculatorapplet/chart_norm.html [Accessed 24 Apr. 2001].

LaRocque, E. 1994. *Violence in Aboriginal Communities*. Ottawa: National Clearinghouse on Family Violence.

Lalonde, M. 1974. *A New Perspective on the Health of Canadians: A Working Document*. Ottawa: Health and Welfare Canada.

Linehan, S. 1992. "Giving birth the 'white man's way.'" *Healthsharing*. Vol. 13. No. 2, pp.11-15.

Lowell, J. 1995. "Rethinking traditions: women taking charge of culture, medicine and each other." *Herizons: Women's News, Feminist Views*. Vol. 9. No. 1, pp.25-26.

MacMillan, H., MacMillan, A., Offord, D. and Dingle, J. December 1996. "Aboriginal health." *Canadian Medical Association Journal*. Vol. 155, pp. 1569-1578.

Manyfingers, B. 1994. *Treaty 7 Community Study: Family Violence and Community Stress*. Unpublished paper submitted to the Royal Commission on Aboriginal Peoples.

Martin, J. and Bell, P. 1991. "Diabetes mellitus in the Native population of British Columbia" in Postl, B., Gilbert, P., Goodwill, J., Moffatt, M., O'Neil, J., Sarsfield, P. and Young, T. [eds.] *Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health*. Winnipeg: University of Manitoba Press, pp. 433-435.

McBride, C. and Bobet, E. 1990. *Health of Indian Women*. Ottawa: Indian and Northern Affairs Canada.

McEvoy, M. and Daniluk, J. 1995. "Wounds to the soul: the experiences of aboriginal women survivors of sexual abuse." *Canadian Psychology*. Vol. 36. No. 3, pp. 221-235.

Namyniuk, L., Brems, C. and Clarson, S. 1997. "Southcentral Foundation - Dena A Coy: a model program for the treatment of pregnant substance-abusing women." *Journal of Substance Abuse Treatment*. Vol. 14. No. 3, pp.285-295.

National Anti-Poverty Organization (NAPO). 1997. "NAPO facts: Poverty in Canada: Some Facts and Figures." http://www.napo-onap.ca/nf-figur.htm [Accessed 24 Apr. 2001]

National Forum on Health February 1997. *Canada Health Action: Building on the Legacy*. Vol. 1. Ottawa: Health Canada.

Native Women's Association of Canada. 1997. *'Hear their Stories': 40 Aboriginal Women Speak*. Ottawa: The Association.

_____. 1996. *Health Children, Healthy Nations: A Framework Document to Support the Well-being of First Nations' Children*. Ottawa: The Association.

Pan-American Health Organization (PAHO). 1999. "Canada: Basic Health Profiles, Summaries 1999." http://www.paho.org/english/sha/prflcan.htm [Accessed 17 Jan. 2001].

Pauktuutit Inuit Women's Association. April 2001. *The Inuit Women's Health Issues Workshop*. Ottawa: The Association

_____. March 2000. *Inuit Women's Health: Overview and Policy Issues*. Ottawa: The Association.

_____. 1998. *Ikajuqtigiinniq: A Resource for Fetal Alcohol Syndrome Prevention and Intervention Work.* Ottawa: The Association.

Robinson, G., Conry, R. and Conry, J. 1985. *The Canim Lake Survey of Special Needs Children.* Vancouver: University of British Columbia.

Royal Commission on Aboriginal Peoples (RCAP). 1996. *Report of the Royal Commission on Aboriginal Peoples: Perspectives and Realities.* Vol. 4. Ottawa: The Commission.

Ship, S. and Norton, L. 2000. "'It's hard to be a woman': First Nations women living with HIV/AIDS." *Native Social Work Journal.* Vol. 3. No. 1, pp. 69-85.

Society of Obstetricians and Gynaecologists of Canada (SOGC). March 2001. "SOGC policy statement: a guide for health professionals working with Aboriginal peoples: Aboriginal health resources." *Journal of the Society of Obstetricians and Gynaecologists of Canada.* Vol. 23. No. 3, pp. 255-261.

Statistics Canada. 2000. *Women in Canada 2000: A Gender-Based Statistical Report.* Ottawa: The Department.

_____. 13 January 1998. "The Daily: 1996 Census: Aboriginal data." http://www.statcan.ca/Daily/English/980113/d980113.htm [Accessed 28 Feb. 2000].

Toronto Star. 12 June 1997. Allan Thompson. "4th Year in a Row! Canada still rated best place to live - UN." http://www.cam.org/~mrci/un.htm [Accessed 20 Feb. 2001].

United Nations Development Program (UNDP). 1999. "Human Development Indicators." http://www.undp.org/hdro/ihpprof.htm [Accessed 23 Apr. 2001]

APPENDIX I
LIST OF CEWH-AFFILIATED INITIATIVES REVIEWED

Maritime Centre of Excellence for Women's Health

1. Barksdale, C., Wills, S., Davidson, K., van Roosmale, E., Loppie, C., Kirkland, S., Unruh, A., Stewart, M. and Williams, D. n.d. *Women's Definitions and Priorities of Health.*
2. Doyle Bedwell, P. n.d. *Off-Reserve First Nations Women's Mental Health: A Proposed Exploration.*
3. Nova Scotia Mi'kmaq Health Research Group. 16 November 1999. *The Health of the Nova Scotia Mi'Kmaq Population: A Final Research Report.*
4. Nova Scotia Mi'kmaq Health Research Group. n.d. *An Exploration of the Stress Experience of Mi'kmaq Female Youth in Nova Scotia.*
5. Pereira, J. n.d. *Perceptions of Access to Ethnomedicine in the Environment: A Preliminary Case Study in the Mi'kmaq Community of Indian Brook.*
6. Van Roosmalen, E. and Loppie, C. n.d. *Women's Perceptions of the Determinants of Health and Well-Being Development Project: Final Report.*

Centre of Excellence for Women's Health - Consortium Université de Montréal

7. Roy, B. and Fecteau, K. 2000. *Parole et pouvoir de femmes des Premières Nations. Manuel pour une prise de parole sur la vie, la santé... le diabète.* Wendake: Commission de la santé et des services sociaux du Québec et du Labrador.
8. Jauvin, N., Clément, M. and Damant, D. July 1998. *L'interrelation entre la santé et la violence.* Sainte-Foy: Centre de recherche interdisciplinaire sur la violence familiale et la violence faite aux femmes.
9. Kennedy, D. April 2000. *Naanduvedidaa Kuv Final Report.* Wikwemikong: Wikwemikong Health Centre.
10. Lavallée, C., Bourgault, C. and Petawabano, B. 31 March 1999. *La santé des femmes cries et inuites: convergences et divergences.* Montréal: Santé Québec.
11. Sioui Wawanaloath, C. 1999. *Atelier de créativité production d'idées et ree a sabilité.* Montréal: Femmes autochtones du Québec.
12. Slapcoff, T. n.d. *Final Project Report on the Urban Aboriginal Women's Wellness Resource Centre in Montréal.* Montréal: Aboriginal Women of Montréal.
13. Tait, C. 1 April 1999. *New Beginnings Project: Wellness Needs Assessment of Aboriginal Women Living in Montréal.* Montréal: Aboriginal Women of Montréal.
14. Tait, C. April 1998. *Aboriginal Women and Maternity: Fetal Alcohol Syndrome.* Montréal: Aboriginal Women of Montréal.

15. Thomas, V. February 1998. *Evaluation, Proceedings and Financial Report of the "Wisdom of Native Women" Wellness Conference for Urban Aboriginal Women Held in Montréal, January 16, 17, and 18, 1998.* Montréal: Aboriginal Women of Montréal.

National Network on Environments and Women's Health

16. Benoit, C. and Carroll, D. 1 March 2001. *Marginalized Voices from the Downtown Eastside: Aboriginal Women Speak About their Health Experiences.* Toronto: National Network on Environments and Health.

Prairie Women's Health Centre of Excellence

17. Elias, B., Leader, A., Sanderson, D., O'Neil, J. and Tate, B. December 2000. *Living in Balance: Gender, structural inequalities, and health promoting behaviours in Manitoba First Nation Communities.*

18. Fillmore, C., Dell, C. and the Elizabeth Fry Society of Manitoba. January 2001. *Prairie Women, Violence and Self-Harm: Draft.*

19. Tait, C. June 2000. *A Study of the Service Needs of Pregnant Addicted Women in Manitoba.* Winnipeg: Prairie Women's Health Centre of Excellence and Manitoba Health.

20. Canadian Centre on Disability Issues and First Nation DisABILITY Association of Manitoba. 20 September 2000. *Aboriginal Women with Disabilities: Remembering Education.* Winnipeg: The Centre.

British Columbia Centre of Excellence for Women's Health

21. Bottorff, J., Sent, L., Browne, A., Balneaves, L., Grewal, S. n.d. *An Exploration of Women-Centred Care in the Context of Cervical Cancer Screening in Ethnocultural Groups.* Vancouver: British Columbia Centre of Excellence for Women's Health.

22. Morrow, M. and Chappell, M. 1999. *Hearing Women's Voices: Mental Health Care for Women.* Vancouver: British Columbia Centre of Excellence for Women's Health.

23. Poole, N. and Isaac, B. 2001. *Apprehensions: Barriers to Treatment for Substance-Using Mothers.* Vancouver: British Columbia Centre of Excellence for Women's Health.

24. Poole, N. 2000. *Evaluation Report of the Sheway Project for High-Risk Pregnant and Parenting Women.* Vancouver: British Columbia Centre of Excellence for Women's Health.

25. Browne, A., Fiske, J. and Thomas, G. 2000. *First Nations Women's Encounters with Mainstream Health Care Services and Systems.* Vancouver: British Columbia Centre of Excellence for Women's Health.

26. Browne, A. Forthcoming. *Improving Health Care Services for First Nations Women: A Community Case Study.* Vancouver: British Columbia Centre of Excellence for Women's Health.

APPENDIX II
LIST OF ABBREVIATIONS USED IN THIS REPORT

AWM	Aboriginal Women of Montréal
BCCEWH	British Columbia Centre of Excellence for Women's Health
CESAF	Centre of Excellence for Women's Health - Consortium Université de Montréal
CEWH	Centre of Excellence for Women's Health
CEWHP	Centres of Excellence for Women's Health Program
CWHN	Canadian Women's Health Network
FAE	Fetal Alcohol Effect
FAS	Fetal Alcohol Syndrome
MCEWH	Maritime Centre of Excellence for Women's Health
NNEWH	National Network on Environments and Women's Health
NWAWHR	National Workshop on Aboriginal Women's Health Research
PWHCE	Prairie Women's Health Centre of Excellence
VNHS	Vancouver Native Health Society